Genetic Moralism and Health

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Abstract: This article examines the moralistic language and arguments used in relation to genetics. The focus is on three practices: (1) the claims that there is a duty to know about one's own genetic makeup, (2) assertions that genetic information should be used to inform reproductive decisions, and (3) the proposition that there are moral reasons to participate in biobank research. With these three, the author contends that there are equally good, if not better, arguments to challenge them from a Millian perspective. Furthermore, especially in the current political climate, there is a need to respect people's privacy concerns.

Keywords: moralism; genetics; genetic information; reproduction; biobanks; informed consent

Introduction

I have been writing on the ethics of genetics, and especially on the ethical issues related to genetic information, for over two decades now, and as far as I see, the core issues debated have remained the same. However, the unprecedented rise in commercial genetic testing and governmental interests in genetic information have, mainly due to the decreased costs of gene testing and genome sequencing, made the issues more pressing than ever. In what follows, I will look at three instances of genetics-related practices where moralistic language and arguments are often used. These are: "one should know about one's own genetic make-up," "one should use genetics to try to make sure that one's off-spring will be healthy" and "one should participate in biobank research."[1] My own normative framework is Millian, and I consider (most) moral arguments beyond the harm principle invalid. Those who disagree with this viewpoint will have issues with my analysis and conclusions.

The right to know and right not to know debate

The right not to know about one's own genetic make-up has been one of the themes I have frequently revisited[2], not least because one's normative position on that has ramifications on many genetic research and testing scenarios.[3] The arguments against the right not to know—or, for the duty to know—are, for the most part, twofold. One line of argument says that it would be good for the person herself to know. The second says that autonomy requires that we have all the relevant information (including genetic). While these, and others, are good and valid reasons for seeking genetic information about oneself, the issues are not as clear-cut as they sometimes seem, and people can have quite legitimate reasons for not wanting to know. However foolish these reasons seem to others, if they are given by a competent adult, they should be respected.

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The first line of argument is in many cases, more paternalistic than moralistic but given that there is considerable overlap between the two, I do not consider that a problem. Rather, in what follows, I will not make a clear distinction between paternalism and moralism.[4,5] There are also many types of paternalism, but defining them is beyond the scope of this paper.[6]

Genetic information can confirm diagnoses, tell us if we are more or less likely to develop certain genetic diseases, and tell us that if we have recessively inherited a gene that can cause health problems in our children. I will discuss the reproductive matters in the next section. Here, I will concentrate on predictive genetic testing, as I think that diagnostic genetic testing should be viewed like any other diagnostic test. Obviously, patients seeking diagnosis would be expected to take the tests needed, especially if they are noninvasive. There is however no duty to take any particular tests, but the patient must understand that by declining the test, her care might be compromised.

With predictive genetic testing, the argument against the right not to know is that without genetic information, we can make bad educational, occupational, marital and lifestyle-related decisions. The idea is that if we know about our genetic dispositions we can make realistic life plans, adjust our lifestyle in an attempt to counteract our genetic predispositions, and, in some cases, opt for regular screenings in the hope of finding diseases early, when they are still curable or more treatable. All of these are well and good, but individual situations vary.

It is argued, for instance, that if one knows that she is not likely to live up to the expected life average, she is able to adjust her life plans accordingly and can make the most of the time that she is likely to have, instead of waiting in vain for leisurely years of retirement she will never have. However, people are different, and whilst some might indeed welcome this kind of information, for others, it could cause anxiety and stress well beyond the so-called benefits. It could cause a person to fall into depression and perhaps even to nurture suicidal thoughts. Furthermore, most genetic information talks about likelihoods, and so the predicted outcome might not happen at all. Our understanding of genes also evolves constantly, and while we might now think that a certain mutation is linked with an elevated likelihood of developing a particular disease, we might later learn that it is only in conjunction with another mutation that the likelihood is increased. In this case, it might turn out that our worry was groundless. And even more, there are many other causes of ill health and death besides our genetic composition. One could well spend thirty years in fear of this or that genetic mutation taking effect, only to catch a deadly viral disease or be killed in a car accident before the fears are realized. In which case, there would have been no point living with the burden of that knowledge in the first place. I must emphasize though, that people are different and for some, all knowledge is welcome and it gives them comfort, while others prefer to leave the future more open. The attitude of the people in the latter group might seem foolish to others, but that is not reason enough to deny competent adults their own path. Generally, I think it would be wise for all people to live like they might die tomorrow, but knowing that they could just as well reach a ripe old age—and anything in between. With or without genetic information, we can never really be sure what tomorrow may bring.

Another argument is that people who are genetically prone to, say, high blood pressure and type 2 diabetes would benefit from this information, as it would allow them to adjust their lifestyles accordingly, and they would thereby have a

better a chance of not actually suffering from these conditions. Again, people are different. Some might indeed need the nudge of genetic information to change their diet and exercise regimens, but others might take a more fatalistic view and conclude that there is no point in trying since they are likely to fall ill in any case. We also need to acknowledge that changing one's lifestyle can be very difficult, and perhaps even impossible for some people. Poverty, and lack of resources and time, are very real problems for many people. Healthy food is, overall, more expensive and more difficult to come by than junk food. And if one works two or three jobs just to get any food on the table, one is very unlikely to have the time to exercise.

It can further be argued that "good" genetic information could have detrimental effect on people. Say, for instance, that someone was told that her risk of developing high blood pressure or type 2 diabetes was significantly lower than the average person's. This could well lead that person to think that they can eat whatever they like and need not worry so much about exercising. Bad diet and lack of exercise can lead to all sorts of other health problems not limited to blood pressure and diabetes. Everyone, regardless of their genetic make-up, would benefit from a balanced diet and regular exercise. We do not need genetic information to know that. If health and realistic plans for one's life are the goals, genetic information can help, but, depending on the person, can also undermine these goals.

The third category of cases mentioned by those who advocate knowing are those genetic diseases, such as certain bowel cancers, that regular screening could help discover them at an early, more curable, stage. If screening is readily available and not unreasonably painful or invasive, there is certainly something to this line of thinking. However, if access to the screening cannot be guaranteed or if it poses an unreasonable burden to the prospective patient, the usefulness of this information should be questioned. What is the benefit of knowing that one might develop a fatal health condition later, which could perhaps be cured if detected early enough, but that the means of detection are not available or are unreasonably burdensome?

There are philosophers who do not really care about the above speculations, which all have to do with the consequences of knowing and not knowing. Some, like Rosamond Rhodes, do engage in these discussions, but, ultimately, for them, the duty to know follows from the Kantian idea of autonomy. Rhodes writes:

> Now, if autonomy is the ground for my right to determine my own course, it cannot also be the ground for not determining my own course. If autonomy justifies my right to knowledge, it cannot also justify my refusing to be informed. [...] From a Kantian perspective, autonomy is the essence of what morality requires of me. The core content of my duty is self-determination. To say this in another way, I need to appreciate that my ethical obligation is to rule myself, that is, to be a just ruler over my own actions. As sovereign over myself I am obligated to make thoughtful and informed decisions without being swayed by irrational emotions, including my fear of knowing significant genetic facts about myself.[7]

This discussion takes the moralism of the 'right to know and right not to know' discussion to a whole new level. It is no longer about what would be, allegedly, good for the person, and therefore, something that she should do. It is now about her moral duties toward herself. According to Rhodes' Kantian reading, we have

a moral duty to acquire all the relevant information. Only this will allow us to be autonomous. On a practical level, I would argue that this is an unattainable condition. Just going about our everyday lives, we would need to have access to a staggering amount of facts and probabilities. Think of all you would need to know to make fully informed decisions, say, about commuting to your workplace or buying groceries. A further point to note is that our understanding of genetics is constantly evolving and there are many instances where the scientists themselves disagree on the meanings of genetic findings. It is unclear whose opinion we should trust. Additionally, this approach would require us, if we wanted to remain autonomous, to constantly stay on top of all information, which is impossible.

This is where those with deontological leanings part ways with the consequentialists. For most consequentialists, respecting autonomy entail duties that others have toward the person, not duties a person has toward herself. A liberal utilitarian, for instance, would rephrase the paragraph as follows:

> Now, if autonomy is the ground for my right to determine my own course *if and when I so wish*, it *can* also be the ground for not determining my own course *if and when I so wish*. If autonomy justifies my right to knowledge *when I want to know*, it *can* also justify my refusing to be informed *when I do not want to know*. [...] From a *Millian* perspective, autonomy is the essence of what morality requires *others to respect in their dealings with* me. The core content of *the duty of others toward me* is *respect for my* self-determination. To say this in another way, *they* need to appreciate that *their* ethical obligation is to *let me* rule myself *if and when and to the degree that I so wish*, that is, to *let me* be a just ruler over my own actions. As sovereign over myself I am *entitled* to make *my own* decisions without being *coerced by the opinions of others*. [Italics indicate our edited text.][8]

Keeping with the Millian ideals that adult human beings of competent minds are allowed to make decisions that are foolish in the eyes of others, let me quote this with Mill's famous example of a dangerous bridge.[9] If you see a person approaching a near-collapsing bridge and you do not know whether she is aware of the bridge's condition, you can stop the person to make sure that they know what they are getting into is not totally safe, but if they still want to proceed, you have no right to stop them, nor are they duty-bound to receive a detailed description of the bridge's weaknesses. Similarly, but not quite, with genetic information. You might be justified in making sure that a person knows that such a thing as genetic information exists and knows what it might be useful for, but beyond that, no one can be justifiably force-fed genetic information about themselves. Furthermore, as I have shown above, since genetic information, in itself, can also cause harm depending on the person and her circumstances, there is even less to support an argument for the duty to know.

Having children, alleged harm to others and symbolic discrimination

Reproductive genetic testing, both preimplantation and prenatal, is sometimes suggested as a means of ensuring healthier babies. The argument here is that these steps should be taken because they provide a way of avoiding preventable harm to future children. There are two main problems this line of thinking presents. First, in what sense is "harm" applicable to future children who might never exist, and second, is it acceptable to decide what kinds of children there should be?

Justifying genetic testing to prevent harm to others is problematic when it comes to future children because in most cases, the child with the genetic defect will never exist, but another child is brought into existence instead. In these situations, we are not normally preventing harm to others, but rather, choosing certain children to be born instead of others. With current technologies there is no one child who can either be born with a genetic defect or without it. It is about choosing which embryos are brought to term and which are disregarded. Perhaps, in the future, we might be able to apply gene therapies prenatally or even before implantation, in which case it would make sense to talk about an ability to prevent harm for the child. Again, it would not be preventing harm, but taking an existing harm away. More crucially, it could be asked in what sense a child who is born with an altered genome is the same child that would have been born had her genome not been altered. The answer depends much on the role we give to our genes in determining who we are.

We could, possibly, talk about harm to others in cases where the child's future life is deemed worse than to never have been born at all. Here we would be, arguably, preventing harm by not letting someone be born. But even here, it is unclear whether "harm-to-others" applies, because there are many who would not consider fertilized eggs, early embryos or even fetuses "other" in the sense meant in the harm-to-others argument. Liberal abortion policies, allowing abortions during the first trimester for almost any reason, reflect this kind of thinking.

In that framework there is no harm in aborting or not implanting (obviously, provided that the mother, and to a degree the father, wants this) whether the embryo has or does not have a genetic defect. There is, however, another moral aspect to choosing to abort, or choosing to disregard an embryo or a gamete, based on its genetic characteristics. This is sometimes called symbolic discrimination. When the point of screening is to detect and eliminate disability, the symbolic message that this, arguably, sends is that the disabled people are less valuable than people without disabilities. A further worry is that this makes actual discrimination of existing disabled people more acceptable, and that in the long run, if there are fewer and fewer disabled people, there will be increasing marginalization of people with disabilities.

"Genome Editing and Human Reproduction,"[10] a recent report from July 2018 by the Nuffield Council on Bioethics in the UK, sparked the debate again. The report actually goes further than the matters discussed here, and cautiously opens the door for the possibility of heritable genome editing of human embryos in the hope of wiping out genetic diseases in certain families for good.[11] Director of the Human Genetics Alert, Dr. David King, argued that this goes against international bans on eugenic genetic engineering[12] and others voiced concerns over the message this sends to—and about—the disabled community, and what this means for humanity as a whole.[13,14] Leon Kass has produced one of the most influential arguments against choosing what kind of children there should be, based on the destructive effect they would, allegedly, have on humanity.[15] Others say that we should see all children as gifts, and argue against genetic selection based on virtuous parenthood.[16,17,18]

Using harm-to-others arguments to justify preimplantation, prenatal and gamete screening is problematic because it is unclear whether the argument is applicable in the first place. Furthermore, the jury is out on whether genetically selecting or engineering future children is morally acceptable.

Biobanks for the benefit of all

The biobank fever started at the turn of the millennium with DeCODE Iceland (established in 1996)[19], followed by the Estonian Genome Foundation (established in 2000)[20]. Both projects aimed to map the genomes of a large part of the population, and combine this with other health data. The Estonian project originally planned on giving each participant a "gene card" which would include their own genetic information and against which they could see if any of the new developments in the field affect them.[21] These never materialized. In reality, both biobanks have gone through considerable difficulties. DeCODE went bankrupt, was first sold to an American company, and is currently under Chinese ownership. The Estonian biobank fell short of its aim of collecting the data of 70% of the population within the first ten years, and went through fiscal rearrangements. The current short-term goal, eighteen years after the rearrangements, is to collect samples from 13% of the population and provide the participants with free DNA-informed lifestyle advice.

Biobanks, both national and private, have since been established throughout the world.[22] The decreasing costs of DNA tests aimed at consumers have allowed companies like 23andme to set up large genetic databanks, from which data can further be sold to third parties. However, according to 23andme, no individual-level information will be shared without explicit consent and no information is provided to law enforcement without a subpoena.[23]

The Finnish biobank law (2012) made it possible to establish biobanks in Finland. On the official page of the overseeing body of Finnish biobanks, a biobank is described as follows:

> Biobank is a collection biological samples and data gathered with the donor's consent for future medical research and product development for healthcare and health promotion purposes. Your consent could be crucial for the development of new medicines and treatments. Your sample could change the world![24]

The emphasis on consent is misleading to say the least, as the original idea behind establishing biobanks in Finland was to make use of the many existing sample collections and related health data. Hundreds of thousands of old samples (taken before September 2013) have been moved from smaller collections at hospitals and research institutions to the new biobanks. For a large number of old samples to be moved to a biobank, donors need not be contacted, and it is currently sufficient to place a notification in a major newspaper. On a personal level, had I not, by chance, seen the ad occupying one-eighth of a page, and written in size-8 font, in the main newspaper in 2014, I would be part of one of the biobanks too. That would have been a violation of my autonomy and privacy.

The general ethos is that biobanks would provide excellent research material for geneticists and epidemiologists, which could then lead to new and improved diagnostic tools, treatments, and knowledge that would help healthcare providers plan for future healthcare based on expected need. The old samples provide a good starting point, but new donors are sought-after to secure the quality of the specimens and longevity of the biobanks. The moralistic tone of new donor recruitment is quite obvious, as evidenced, for instance, by the webpage of the Finnish biobank overseer: "Your consent could be crucial for developing new medicines

and treatments. Your sample could save the world!"[25] A good person would want to help develop new medicines and treatments! If you do not participate, you might be harming people who could otherwise be cured!

There might indeed be benefits from biobank research, and we have already seen some in the form of increased knowledge. However, to whom and when the more tangible benefits will fall, and at what cost, is what concerns me. A somewhat abstract cost, which I nonetheless consider to be of great importance, is the watering-down of some of the key research ethics principles by biobank research.

Informed consent became a key requirement for research on humans after the Nuremberg trials.[26] At first, it was mainly to protect research subjects from physical risks and discomforts that they did not consent to, but it quickly came to include wider personal risk assessments and value judgments. Now with biobanks, informed consent allegedly does not work, because biobanks are supposed to function as sources for an unknown number of future research projects, and requesting consent for each one of them would be, among other things, expensive and time-consuming. Additionally, many have argued that since there is no real physical risk to the subjects after their samples have been obtained, sacrificing informed consent might not be that problematic. I beg to differ.

The physical risk is only one aspect of why informed consent has been held valuable. The other parts have to do with the acceptability of the proposed research project and its goals, the funding of the research, the affiliations of the researchers, and the overall risk assessment as judged by the research participant. To forego all these because it would be good for science, and arguably, for society, would be to disrespect the autonomy of the research subjects.

Furthermore, apparently, it is no longer the case that "the interests and welfare of the human being shall prevail over the sole interest of society or science."[27] But rather, the other way around, as the interests of the individual can be compromised if doing so is seen to benefit science and society.

Allowing the needs of science to set the limits of ethics in the case of biobanks could set a dangerous precedent when it comes to research ethics generally. If informing research subjects, for instance, about who is conducting the research, for what purpose, and what the long-term ramifications of the research project could be is not necessary with biobanks, why would it be required in other kinds of research projects? Why would research ethics committees not focus on the overall acceptability of the research projects, like they are doing with biobanks, with informed consent limited to physical risk and discomfort?

I would assume that many of us would be uncomfortable with reducing the information given to research participants to physical risks only, and I would further predict that fewer people would participate in research if only very limited information was given. I also find the practice of relying on ethics committees to approve or disapprove biobank research projects questionable. Assessments of risk and value judgments are personal choices, and cannot be performed by a proxy who might share the values of the research subjects. The matter is further complicated by the fact that we do not know what kind of research, by whom it will be done, and for what purposes it will be done in the future. It is additionally possible that what we learn about genes will transform our understanding of health and illness, and with such drastic changes in insight, one would be very reluctant to give "open" or a "broad" consent for biobanks samples, while leaving the rest to the ethics committees. There could, however, be people who have more faith in

science, authorities, and ethics committee, and who would be willing to waive their decisional power when it comes to biobank research. As a Millian, I would have to allow them this choice, even if I think it foolish. I would however suggest calling the consent they give "blind consent," instead of "broad" or "open," to make it clear that at the time of giving consent, they really cannot know what they are getting into.[28]

Some biobanks leave participants the option of withdrawing their sample later. Most however come with caveats stating, for example, that it might not be possible to identify all the studies one's sample is a part of and that there might be some ongoing studies from which the sample cannot be withdrawn without compromising the study. Having a right to withdraw is important, but given that this is almost impossible to completely guarantee (parts of one's data will always stay somewhere out there), it is not good enough to alleviate my concerns.

As for the benefits of biobank research, it will undoubtedly increase our understanding of genes and the way they contribute to our health and illness. Eventually, this is likely to lead to better medicines and treatments. Biobank research has already contributed to identifying a number of genetic mutations that are linked to various gene-based diseases. Our ability to diagnose has advanced much quicker than our ability to treat, which can be seen as a problem. I would further argue that the distribution of possible benefits is unlikely to be even, and that genetic information can be used against those who have contributed to the biobanks.

Countries with national health services are struggling with rising health care costs, and aging populations. Prioritization, more and less transparent, is a reality everywhere. In Finland, much of this hidden behind the so called "Current Care Guidelines."[29] The simple fact is that not all health needs can be met, and even fewer will be in the future. Those advocating biobank research seem to believe that biobanks will end up providing health benefits for all. I find this very unlikely.

We all carry mutations in our genomes, and with the advances in genetics, more and more of these can be identified. This will mark a huge rise in various potential preventive measures, from lifestyle and diet advice, to targeted screening programs and new inhibitory medications. Some pro-biobank people argue that our ability to offer better-targeted screenings to those with an elevated risk will lower the costs of preventive medicine. Others remind us that preventive medicine is cheaper than treating the diseases themselves. With all of us most likely eventually falling into one risk bracket or another, I do not see how this will help anything. The current medical needs will not go away quickly, and rationing is already necessary. Where will all the resources come from, first to educate healthcare professionals so that they can offer gene-based dietary and healthcare advice, and then to fund new screening programs and the like?

The most likely beneficiaries of the new treatments and medicines are those already better-off, who can afford to buy them, and the companies that make and sell them. And I would not be at all surprised if one's genome will be, in national health systems, increasingly used as an exclusion criterion rather than one of inclusion. With the constant need to reduce healthcare costs, any excuse not to treat certain groups of people would be made use of.

What if, by some miracle, all the promises come true and there are also enough resources for counseling, screening, and personalized treatments, and the average

life expectancy rises to 90-95 years of age? Unless genes somehow allow us to target mental and physical aging, we are possibly looking at most of the population needing 24-hour care for the last 5, 10, or 15 years of life. There will never be a public health budget that could meet that demand. Something, somewhere would have to be cut.

If the goal of all healthcare related projects is to increase overall wellbeing and health, the resources used for genetic research could be used to fix the existing systems. Educating more nurses and doctors and directing funds to the care of the elderly would go a long way. Much of current suffering could be eliminated, for instance, if waiting times for operations could be shortened, more treatments and medications covered by national health care system and healthcare professionals adequately compensated, rested and stress-free. The latter would bring great improvements to the quality of care and the patient experience. On the global level, providing, say, malaria vaccinations, clean drinking water, nutrition, contraceptives, and access to even basic universal healthcare, would provide, I would claim, more QALYs than current genetic research will.

My claims in the above can obviously be contested, but there's one more aspect I would like to bring to the table. Only a few years ago, reminding people of how the detailed records the Germans had of their citizens in the early 20th century were used against certain parts of the population, was met with condescending indifference: "Hitler is not coming back." Not so much anymore. We live in a world of political turmoil. Laws are revoked and international treaties abandoned. There's no way of knowing what the legal future uses of genetic information will be. It is very reasonable to concerned about the future uses of one's genetic information. Not getting tested, or refusing to participate in biobanks that cannot guarantee anonymity, are reasonable precautions to take in the modern world. Using one-sided moralistic language and arguments to convince people to do otherwise is misleading, to say the least.

For instance, it is now mostly illegal for insurance companies to request known genetic information, but this is likely to change. The insurance business works on probabilities and unknowns, but as more and more people get themselves tested, many of them will use this information to optimize their health and life insurances accordingly. The current insurance system cannot survive this. Insurers are already allowed to ask for certain medical information and it would only be a very small step to add genetic information to the list.

Furthermore, with the national health services struggling with increasing costs of healthcare and aging populations, and governments more generally struggling to maintain basic services and infrastructure, the need to save money and streamline across the healthcare services seems never ending. Perhaps, in the future someone comes up with the idea that to save money, people should be guided from early on toward professions and lifestyles that make the best use of the genetic makeup they were born with. By this I mean, the possibility of using genetic information, however statistical in nature, to inform the educational and occupational options open to individuals.

Last, but not least, I would think that unless the political climate in the world soon takes a different turn, worrying about possible eugenic uses of genetic information in the near future is not unfounded. If these matters are not taken seriously, genetic discrimination could be a reality sooner than we think.

Conclusions

Moralistic and paternalistic arguments are often used to convince people that they should seek genetic information about themselves and their prospective offspring, and participate in biobank research. While I do not wish to deny that increasing understanding of genetics is likely to lead to better diagnoses, medications, and treatments, I am doubtful as to whether these will be for the benefit of the many, and think that they could actually work against the individuals participating. Furthermore, I do not think that the expected benefits of biobank research justify forfeiting informed consent. People should however be given the right to waive their right to informed consent, if they so choose, and to give blind consent instead. I have some reservations when it comes to people who have or will have children, as their genetic information will reveal parts of their children's genetic make-up in a process the children have no say in, but that discussion is beyond the scope of this paper.

I do not think that we should discard informed consent simply because it would benefit science. Science benefits from the existence of biobanks and as such, I do not think it is unreasonable to require that each new research project requests informed consent. The data and samples are, unlike before, available to the scientists, and all they need to do is request proper consent before proceeding with the study.

Data security and privacy concerns, as well as worries that a person's genome could be used against her, are not unfounded in a world where the most secured computers have been hacked, and where fascism is raising its ugly head. People should not be judged for choosing to try to protect their genetic privacy, especially when it is not clear who will benefit from advances in genetics.

Notes

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